

Survey of Bereavement Practices of Cancer Care and Palliative Care Physicians in the Pacific Northwest United States

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Abstract

Purpose: Physicians caring for patients with cancer frequently encounter individuals who will die as a result of their disease. The primary aim of this study was to examine the frequency and nature of bereavement practices among cancer care and palliative care physicians in the Pacific Northwest United States. Secondary aims included identification of factors and barriers associated with bereavement follow-up.

Methods: An institutional review board (IRB) –approved, anonymous online survey of cancer specialists and palliative care physicians in Alaska, Washington, Oregon, Idaho, Montana, and Wyoming was performed in fall 2010. Potential participants were identified through membership in national professional organizations. Summary statistics and logistic regression methods were used to examine frequency and predictors of bereavement practices.

Results: A total of 194 (22.7%) of 856 physicians participated in the online survey, with 164 (19.1%) meeting study inclusion criteria. Overall, 70% of respondents reported always or usually making a telephone call to families, sending a condolence letter, or attending a funeral service after a patient's death. The most common perceived barriers to bereavement follow-up were lack of time and uncertainty of which family member to contact. Sixty-nine percent of respondents did not feel that they had received adequate training on bereavement follow-up during postgraduate training.

Conclusion: Although a significant portion of respondents engaged in some form of bereavement follow-up, the majority felt inadequately trained in these activities. Efforts to identify available resources and address bereavement activities in postgraduate training may contribute to improved multidisciplinary treatment of patients with cancer and their families.

Introduction

Physicians caring for patients with cancer encounter varying stages of illness, with a significant proportion of patients ultimately dying as a result of their disease. In addition, after a patient's death, the bereavement experience of surviving family and caregivers can be associated with increased morbidity and mortality.¹⁻¹⁰ The effect of death and dying on a patient's larger social network has led to an ongoing evolution of the physician's role in comprehensive cancer care. In 1998, the American Society of Clinical Oncology (ASCO) published the special article *Cancer Care During the Last Phase of Life*.¹¹ Among its recommendations, this publication advocated for the broader use of palliative care and supported the longitudinal involvement of cancer care physicians throughout the course of disease. Some have supported the belief that this longitudinal involvement includes the period after death.¹²⁻¹⁴

Follow-up with bereaved family and caregivers is viewed as an essential component of good palliative care.¹⁵⁻¹⁸ The lack of such follow-up can result in feelings of abandonment and decreased satisfaction with care.¹⁹⁻²² Recent studies of physicians caring for patients with cancer have demonstrated that bereavement can vary significantly by specialty and practice as well as according to resource availability and individual physician opinions.²³⁻²⁵

The primary objective of our study was to assess the frequency and nature of bereavement follow-up among cancer

care and palliative care physicians in the Pacific Northwest United States. For the purpose of this article, we define bereavement follow-up to include all those surveyed activities after patient death in which a physician has contact with surviving family members or caregivers. Secondary objectives included examination of factors associated with engaging in bereavement follow-up activities in this population and comparison of the participation in such activities by medical specialty.

Methods

Study Population

Eligible study participants included attending radiation oncologists, medical oncologists (including pediatric oncologists), surgical oncologists (including surgical subspecialties), and palliative care or hospice physicians who, at the time of survey, were directly involved in patient care in Alaska, Idaho, Montana, Oregon, Washington, and Wyoming. Participants were identified through 2010 membership directory listings of ASCO, the American Society for Therapeutic Radiology and Oncology, and the American Academy of Hospice and Palliative Medicine. Potential participants were initially contacted via directory-listed e-mail addresses in October 2010. This e-mail communication included a description of the project and invitation to participate by agreeing to electronic consent and completing an anonymous online survey. Reminder e-mails were

sent to nonresponders at 2 and 6 weeks after the initial invitation. Because of suboptimal response rates after e-mail contact, an approved protocol modification allowed for a single postcard reminder to be sent to nonresponders. No compensation was offered for participation in the study. This study was reviewed and approved by the Oregon Health & Science University Institutional Review Board (IRB00006539).

Survey Instrument and Data Collection

The survey was developed using the Research Electronic Data Capture (REDCap) survey administration tool supported at Oregon Health & Science University by the Oregon Clinical and Translational Research Institute. To aid in comparison, survey content was based largely on two recent studies of the self-reported bereavement practices of cancer care physicians.^{23,25} This included 18 demographic questions regarding characteristics (sex, age, race, ethnicity, religion) and practice composition (medical specialty, tenure, type of practice, presence or absence of palliative care and bereavement programs, work hours, number of new patients per week, proportion of patients with advanced illness, monthly number of deaths, and proportion of time spent on patient care, research, teaching and/or administrative activities).

Investigative questions and opinion statements were designed using five-point Likert scale responses. Seven questions measured frequency of participation in bereavement follow-up activities using response anchors of never and always. Activities surveyed included initiating a telephone call to the family, sending a condolence letter or card, attending a funeral or memorial service, initiating or attending a family meeting, making oneself available to answer telephone calls, and referral to bereavement counselor, support program, or support group.

Eight questions were used to assess the level of agreement between the respondent's relationship with patients and personal feelings about bereavement follow-up using response anchors of strongly disagree and strongly agree. Seven questions measured the importance of perceived barriers to bereavement follow-up. The final four questions of the survey assessed the importance level of services a bereavement program may offer. The full survey is available from the corresponding author.

Statistical Analyses

Summary statistics were used to describe characteristics of respondents and frequencies of bereavement follow-up activities. Data are presented as frequency counts, percentages, and medians, as indicated. Comparison of bereavement practices between palliative care physicians, medical oncologists, and radiation oncologists was performed using Fisher's exact test, with a predefined level of significance of $P \leq .05$. Surgical oncologists were excluded from specialty comparison because of the small number in our sample (eight participants, representing 5% of total participants). The small number of pediatric oncologists (five participants) was grouped with medical oncologists for the purposes of interspecialty comparison.

We considered physician-initiated telephone calls, sending condolence letters or cards, and attending funerals as active

forms of bereavement follow-up, as in another recent study of bereavement practices.²³ A binary measure summarizing participation in active bereavement practices was derived for each physician by assigning a score of 1 to 5 to the Likert-scale responses of never to always, respectively. For example, a participant who indicated never performing an activity would receive a score of 1, performing an activity sometimes would receive a score of 3, and always performing an activity would receive a score of 5. Each physician's responses to the three active practice items were summed and then divided by three to obtain a mean active bereavement score. This mean score was then dichotomized into ≥ 3 (sometimes, usually, or always) and < 3 (rarely or never).

Respondent demographics, physician opinions, and perceived barriers were explored as possible predictors of active bereavement practices (mean active bereavement score ≥ 3) using univariate and multivariate logistic regression. Physician opinion predictors were dichotomized into > 3 (agree or strongly agree) and < 3 (disagree or strongly disagree). Perceived barrier predictors were dichotomized into ≥ 3 (somewhat important, important, or very important) and < 3 (not very important or not important at all). Multivariate analysis was conducted using stepwise selection method with cutoffs of $P \leq .25$ for entry into the model and $P \leq .05$ to remain in the model. Odds ratios (ORs) are presented with 95% CIs. All analyses were conducted using the statistical software package SAS version 9.2 (SAS Institute, Cary, NC).

Results

Characteristics

A total 194 (164 after e-mail solicitation, 30 after additional postcard mailing) of 856 contacted potential participants accessed the online survey tool, for an overall response rate of 22.7%. Four respondents declined further participation at the electronic consent statement. Excluded respondents included 23 who were not attending physicians and three who were not currently involved in direct patient care. After these exclusions, a total of 164 participants (19.1% of total contacted) met study inclusion criteria.

The median age of respondents was 52 years, and a majority of respondents were white men (Table 1). Medical oncology was the most common specialty (41%), followed by palliative care (24%) and radiation oncology (23%). Seven other specialties reported were family medicine ($n = 3$), internal medicine ($n = 1$), internal medicine and pediatrics ($n = 1$), critical care ($n = 1$), and psychiatry ($n = 1$). Approximately half of respondents had been staff physicians for > 15 years. A slight majority of respondents reported working in community hospitals. Eighty percent of respondents stated that their facility had a functional palliative care program.

Bereavement Practices

Overall, 89.4% of respondents (95% CI, 83.6% to 93.3%; Fig 1) reported that they would always or usually be available to answer telephone calls from a patient's family or caregiver. Re-

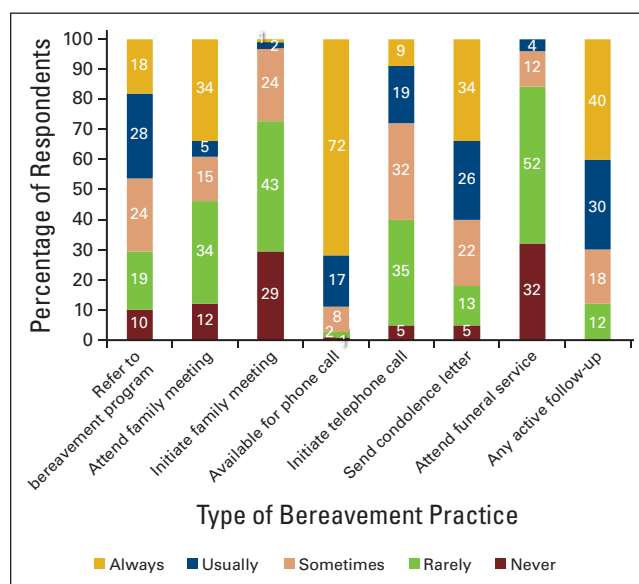
Table 1. Respondent Characteristics (n = 164)

Characteristic	No.	%
Sex		
Female	56	34
Male	107	66
Age, years		
Median	52	
Range	32-73	
Ethnicity		
Asian	13	8
Hispanic/Latino	4	2
White	142	88
Other	3	2
Religion		
Christian	68	42
Jewish	14	9
Hindu	1	1
Other	12	7
Unaffiliated (eg, atheist, agnostic)	57	35
Prefer not to answer	10	6
Specialty		
Medical oncology	67	41
Palliative care	40	24
Radiation oncology	36	23
Surgical oncology	8	5
Pediatric oncology	5	3
Other	7	4
Tenure as staff physician, years		
≤ 5	29	18
5-10	29	18
11-15	21	13
> 15	85	51
Practice location		
Community hospital	64	39
Academic hospital	39	24
Cancer center	40	25
Other	20	12
Palliative care program		
Yes	131	80
No	31	19
Unsure	2	1
Bereavement program		
Yes	74	45
No	66	40
Unsure	24	15
Average work hours per week		
≤ 40	28	17
41-50	43	26
51-60	51	31
61-70	26	16
> 70	16	10

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Table 1. (Continued)

Characteristic	No.	%
No. of new patients per week		
≤ 5	39	24
6-10	86	53
11-15	17	10
16-20	6	4
> 20	14	9
Patients with advanced illness, %		
≤ 25	78	48
26-50	48	30
51-75	9	5
> 75	27	17
Average No. of deaths per month		
Median	4	
Range	0-60	
Time spent on patient care, %		
≤ 25	18	11
26-50	20	12
51-75	26	16
> 75	99	61
Time spent on research, %		
≤ 25	133	83
26-50	16	10
51-75	6	4
> 75	4	3

**Figure 1.** Frequency of surveyed bereavement practices.

garding family meetings, 72.0% (95% CI, 64.7% to 78.4%) of respondents reported rarely or never initiating such meetings. When asked about attendance at family-initiated meetings, 45.6% (95% CI, 38.1% to 53.4%) reported that they would never or rarely attend such meetings, and 38.7% (95% CI, 31.5% to 46.5%) would always or usually attend meetings at a

family's request. Almost half of respondents would always or usually refer family members and caregivers to bereavement programs.

When focusing on active bereavement practices, 69.8% (95% CI, 62.3% to 76.3%) of respondents reported always or usually performing at least one of the activities of making a telephone call to families, sending a condolence letter, or attending a funeral service. The most commonly performed activity was sending a condolence letter or card (Fig 1). Between specialties, medical oncologists were more likely to report always or usually placing a telephone call to family (42.3% *v* 15.0% of palliative care physicians and 11.1% of radiation oncologists; *P* = .002) and sending a condolence letter (71.8% *v* 55.0% of palliative care physicians and 33.3% of radiation oncology physicians; *P* = .004). Referral to bereavement support groups was reported by 75.0% of palliative care physicians compared with 38.0% of medical oncologists and 33.3% of radiation oncologists (*P* = .002).

Physician Opinions

The majority of physicians in each specialty agreed that they liked to meet a patient's family and treat patients as part of a family unit. Medical oncologists reported a higher frequency of tending to get attached to patients, feeling a sense of failure after a patient's death and believing that physicians had a responsibility to write a condolence letter. Palliative care physicians reported the lowest frequency of feeling anxious speaking to families after a death. The majority of respondents in each specialty (68.3% overall) did not feel that they had received adequate training on bereavement follow-up during their residency or fellowship training (Table 2).

Perceived Barriers and Needs From Bereavement Programs

The most commonly perceived barrier of bereavement follow-up among all specialties was lack of time (62.4% overall). A greater proportion of radiation oncologists cited lack of bereavement support services, uncertainty about which family member to contact, and feeling uncomfortable about what to say as important barriers. Of those services surveyed, respondents believed that providing a list of bereavement support services available in the community and identifying the appropriate family member to contact were the most important services that a bereavement program might offer (data not shown).

Logistic Regression Analysis

Univariate predictors that were positively associated with active bereavement follow-up included specialty of medical oncology, presence of a palliative care program, working > 60 hours per week, tendency to get attached to patients, and belief that physicians have a responsibility to write a condolence letter. Feeling uncomfortable about what to say was negatively associated with active bereavement follow-up. On multivariate analysis, specialty of medical oncology (OR, 4.68; 95% CI, 1.61 to 13.62), presence of a palliative care program (OR, 3.24; 95% CI, 1.10 to 9.58), and belief that physicians have a responsibility to write

a condolence letter (OR, 6.62; 95% CI, 2.16 to 20.33) remained significant positive predictors of active bereavement follow-up. Feeling uncomfortable about what to say in addition to lack of bereavement support services were significant negative predictors of active bereavement follow-up (OR, 0.31; 95% CI, 0.11 to 0.87 and OR, 0.38; 95% CI, 0.15 to 0.98, respectively).

Discussion

We surveyed a US population of cancer care physicians regarding their participation in common bereavement activities after the death of a patient. An important distinction in these activities is that although bereavement counseling has the potential to intervene and affect complicated grief,²⁶ a majority of surveyed activities represent expressions of condolence. The extent to which condolence expressions have an impact on health outcomes is unknown, although we propose it affords potential contact to identify those who may benefit from counseling. Seventy percent of our respondents referred to a bereavement program at least sometimes; however, the circumstances surrounding this referral and any possible impact on the bereaved are beyond the scope of our study.

Interpretation of the high bereavement follow-up rates seen in our study is significantly limited by its disappointing 22% response rate. Originally, we suspected that e-mail solicitation may have either been overlooked or blocked by e-mail filtering programs, but additional contact by US mail showed only small recruitment benefit. Two similar studies of physician bereavement practices have been performed in Canada and Israel, each demonstrating an approximately 70% response rate.^{23,25} Similar recruitment methods were used, although one study did provide a small incentive for participation.²³ Because physician bereavement practices remain a relatively understudied area, to place our findings within the proper context, we offer comparisons to these two similar studies while acknowledging that the substantial differences in participation rates and presence of biases challenge the validity of direct comparison.

In a similar population of Canadian physicians, Chau et al²³ found that one third of respondents usually or always performed the active practices of sending a condolence card, attending a funeral, or, most commonly, placing a telephone call to families. More than two thirds of respondents in our regional domestic survey reported regularly participating in at least one of these activities. Canadian physicians with access to a palliative care program were less likely to perform bereavement follow-up, which the authors suggested may have represented delegation of bereavement follow-up to palliative care services, a finding absent in our study. Finally, survey of the Canadian physician group found that palliative care physicians were the most likely group to perform active bereavement follow-up. In contrast, we found that medical oncologists were most likely to engage in active bereavement follow-up. It has been demonstrated that often, referral to palliative care physicians occurs relatively late in the course of disease.²⁷⁻²⁹ It is possible that delay in palliative care referral may result in a shorter timeframe

Table 2. Opinions Regarding Patients and Bereavement Follow-Up According to Specialty

Opinion	Radiation Oncologists (n = 37)		Medical Oncologists (n = 72)		Palliative Care Physicians (n = 40)		P
	No.	%	No.	%	No.	%	
Tend to get attached to patients							.003
Strongly disagree or disagree	7	19.4	4	5.6	1	2.5	
Neutral	7	22.2	12	16.9	17	42.5	
Agree or strongly agree	21	58.3	55	77.5	22	55.0	
Prefer not to show true feeling							.23
Strongly disagree or disagree	28	77.8	60	84.5	38	95.0	
Neutral	5	13.9	7	9.9	2	5.0	
Agree or strongly agree	3	8.3	4	5.6	0	0.0	
Like to meet family members							.50
Strongly disagree or disagree	0	0.0	1	1.4	0	0.0	
Neutral	4	11.1	4	5.6	1	2.5	
Agree or strongly agree	32	88.9	66	93.0	35	97.5	
Like to treat family unit							.003
Strongly disagree or disagree	3	8.3	2	2.8	0	0.0	
Neutral	7	19.4	5	7.0	0	0.0	
Agree or strongly agree	26	72.2	64	90.1	40	100.0	
Physicians have responsibility to write condolence letter							.001
Strongly disagree or disagree	15	41.7	20	28.2	10	25.0	
Neutral	17	47.2	17	23.9	18	45.0	
Agree or strongly agree	4	11.1	34	47.9	12	30.0	
Feel anxious speaking to family after patient death							.02
Strongly disagree or disagree	20	55.6	46	64.8	35	87.5	
Neutral	9	25.0	11	15.5	2	5.0	
Agree or strongly agree	7	19.4	14	19.7	3	7.5	
Feel sense of failure							.001
Strongly disagree or disagree	25	69.4	53	74.7	39	97.5	
Neutral	7	19.4	5	7.0	1	2.5	
Agree or strongly agree	4	11.1	13	18.3	0	0.0	
Received adequate bereavement training in residency/fellowship							.14
Strongly disagree or disagree	25	69.4	47	66.2	28	71.8	
Neutral	8	22.2	12	16.9	2	5.1	
Agree or strongly agree	3	8.3	12	16.9	9	23.1	

in which to develop the physician-patient bond that makes follow-up more likely.²⁵

Seventy-four percent of Israeli oncologists surveyed by Corn et al²⁵ reported frequently or occasionally participating in bereavement rituals, with 26% reporting that they never engaged in any sort of bereavement rituals. The likelihood of bereavement activity participation was significantly associated with the presence of a special bond with patients. Grouping the practices of attendance at funerals, visitations, and memorial services together, they found that 29% of respondents frequently or occasionally attended these events. In comparison, 16% of our respondents reported always, usually, or sometimes attending a funeral or memorial service. This discrepancy in ritual attendance rates may be explained by differences in culture, practice of medicine, or perceived expectations and responsibilities. A

consistent barrier reported in these studies as well as ours was lack of time.

From a historical perspective, the physician's letter of condolence is one of the oldest enduring forms of grief expression in medicine.^{12,30-32} As the most common active practice in our study, it is not surprising that the belief that this form of communication was a physician's responsibility was positively associated with active follow-up. Taking into consideration the self-reported lack of training as well as feelings of uncertainty about what to say, perhaps a good starting point is to revisit training in this dying art. Various authors have suggested the essential components of a condolence letter include acknowledgment of loss, recognition of one's role in care, mention of a personal quality or memory of the deceased, an offer to remain available for support or questions, and expression of sympathy.^{31,33} Iden-

tification of the appropriate family contact is also key for such communication.

The perceived lack of adequate training regarding bereavement activities during residency or fellowship has been demonstrated in other studies of physicians dealing with end-of-life issues.³⁴⁻³⁸ Additionally, barriers that were negatively associated with active bereavement follow-up included lack of bereavement support resources and feeling uncomfortable about what to say. Since ASCO developed recommendations a decade ago,¹¹ there has been an expansion of palliative care rotations as well as improvements in educational resources to specifically address the need for education in end-of-life care.^{16,39} Palliative care programs have also greatly expanded, perhaps causing some to assume embedded bereavement follow-up mechanisms. In practice, bereavement follow-up is often performed by various members of the health care team.^{24,40} It is important to consider that although follow-up in general is welcomed, studies have demonstrated that family members feel it is important to have contact with a patient's physician.^{20,41} Determining the direct impact of these efforts on the bereaved will require longitudinal study.

We do not presume that lack of participation in bereavement follow-up is the result of avoidance. There are countless factors that influence an individual's decision to reach out to a patient's family. Although the individual needs of the bereaved can be highly variable,⁴² a significant proportion of families express the desire for and satisfaction with such activities.^{19,40,43-45} As mentioned, the extent to which direct contact through offerings of condolence ultimately leads to referral for support or counseling would be a point of interest for future study.

We acknowledge the low response rate to our survey significantly limits its generalizability, and the high rates of participation in bereavement follow-up likely reflect contribution from both response and social desirability biases. Because of the design of our study, it was not possible to determine difference in demographics from respondents and nonrespondents. To aid in comparison, the methods selected for this study mirror those of a similar study of bereavement practices among cancer care physicians.²³ However, given our smaller sample size, such methods may lack sufficient statistical power. Finally, although we expected membership in the surveyed professional organizations to represent the majority of physicians we were interested in targeting, there likely remains a substantial unsurveyed population.

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In conclusion, a large proportion of our study respondents reported engaging in bereavement follow-up, with a concurrent perceived lack of training in these activities. Although the role of the physician in bereavement follow-up is not clearly defined, efforts to improve communication, identify available resources, and address bereavement activities in postgraduate training and maintenance of certification may, in part, lead to improved multidisciplinary treatment of patients with cancer, their families, and caregivers. Future studies linking physician training and practices with the longitudinal family and caregiver adjustment to loss are needed.

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